



## EMOTIONAL CHALLENGES FACED BY PEOPLE WITH HIV/AIDS (PWHA)

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### ABSTRACT

**Background:** There are 34 million people living with human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) worldwide. Most, live in Africa, and in 2011, the highest death rates were in South Africa. HIV infection has a major impact on the mental health of the person, which has a chance of causing cognitive impairment, mood and anxiety disorders, and even psychotic manifestations. Emotional problems impair the quality of life of the person, including being stigmatized.

**Objectives:** To explore the emotional challenges faced by people with HIV/AIDS (PWHA).

**Method:** During initial search, 128 articles were retrieved and after screening 10 articles were selected, which meet the eligibility criteria. These articles were searched from Pub Med, EBSCO, and DELNET from 2007 to 2016.

**Results:** HIV/AIDS led to external and internal (self) stigmatization, and affected almost all areas of the lives of PLWHA. Stigmatization and the progression of the disease led to psycho-emotional disturbances, job losses, poverty, dependence, the strain or disruption of relationships and painful bodily symptoms. Some PLWHA felt that finding a job would solve most of their problems and religious belief, spirituality were also used to cope with life. The emotional support by other PLWHA was to be more meaningful than counseling by healthcare workers. Conclusion: Internal and external stigmatization seemed to characterize the emotional experience of participants and negatively impacted on the lives of PLWHA, as well as strategies to combat the HIV/AIDS epidemic. Stigmatization needs to be prevented at all levels for the quality of life of the person, by developing targeted and contextually sensitive anti-stigmatization messages or intervention, which is effective in minimizing the HIV/AIDS stigma.

**KEYWORDS:** Emotional challenges, Quality life, HIV/AIDS, Stigmatizati.

### INTRODUCTION:

Human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV/AIDS) is wide spread disease caused by infection with the human immunodeficiency virus (HIV) that directly attack to human immune system.

HIV/AIDS is a worldwide pandemic. As of 2014, estimated 37 million people affected with HIV and 2 million were arrived with new infections. In sub-Saharan Africa, approximate 25.8 million people living with HIV and estimated about 70% affected globally. In 2019, it estimated that 12% of people living with HIV. And around 250000 were death recently (WHO,2016).

#### In India

According to 2015, adult (15–49 years) HIV prevalence was approximately 0.26%, it likely to be 0.30% males and 0.22% females. In India, state Manipur showed the highest rate with adult HIV. In India, total no. of people affected with HIV approximately 21.17 lakhs and around 87 thousands with new HIV infections in 2015. Approximately 67.6 thousand people died in 2015 (NACO, 2015). HIV infection is a major problem of mental health. Psychological problem effect the quality of life of an individual due to stigma attached to disease. Avoidance regarding transmission is one of the major reasons to increase psychological problem that includes helplessness, limited physical activities, suicidal thought, mood changes, and feeling of guilt. It decreased productivity of life. Aim of nursing to enhance practical nursing while giving care to HIV infected individual. Through this, nursing knowledge can be extended to provide quality of care both mentally and medically.

### MATERIALS AND METHODS:

This narrative review was intended to explore, describe, and interpret the emotional experiences, themes & pattern of persons living with HIV/AIDS. The initial workout starts with the qualitative research review literature.

Eligibility criteria of selecting the articles:

a. **Study design:** Only qualitative research articles with any of its design like phenomenological, grounded theory were included.

b. **Timing of published articles:** Recent and up to date articles was included which ranged from 2007 to 2016.

c. **Language:** Articles published in English language were considered.

d. **Availability of full text:** Available full text articles were included in the study.

Full text articles were searched from Pub med, Google scholar, EBSCO, DELNET database.

e. **Type of sample:** People infected by human immune deficiency virus were selected as a sample and age limit above 18 years.

f. **Sample size:** 6 or more people living with HIV/AIDS were considered.

### PRISMA FLOW CHART

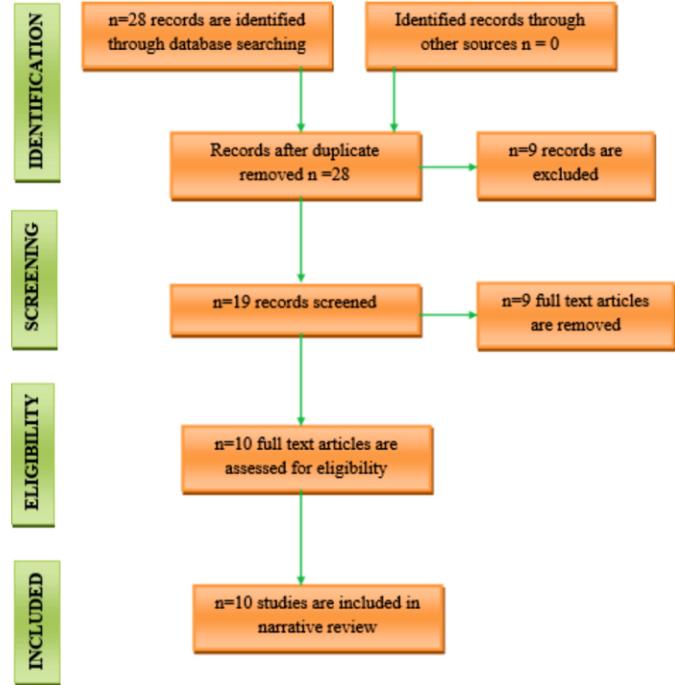


Figure 2: PRISMA flow chart

Table: 1  
Data extraction table

| SL NO | PROBLEM STATEMENT/ AUTHOR                                                                                                                                                                       | OBJECTIVES                                                                                                                                         | PLACE OF RESEARCH & YEAR                                                | VARIABLES                                        | TOOLS                                               | TIME DURATION     | OUTCOMES                                                                                                                                                                                                                                                                                                                       | REMARK                                                                                                                                                                                                                     |
|-------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------|--------------------------------------------------|-----------------------------------------------------|-------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1.    | Assessment of Emotional Problems faced by People Livwith HIV/AIDS and to study the role of family support and role of a counsellor to manage the Emotional Problems.<br><br>Manjula A. R. et.al | 1. To assess the emotional impact on the respondents<br>2. To assess the level of family support.                                                  | KMC Hospital Mangalore ShreeDevi College, Mangalore. India.<br><br>2016 | Emotional Problems faced by People with HIV/AIDS | Structured questionnaire                            | 6 months          | Emotional problems have major impact on the health of the respondents when they come to know about their HIV status. The data in this study shows that 82.3% of the respondents have emotional problems like guilt, feeling of hopelessness, anger, shocked etc. and among them only 17.7% managed these problems efficiently. | This study highlighted that extension of ART treatment is improved when high family support is there.                                                                                                                      |
| 2.    | The lived experience of Indian women with HIV/AIDS in South Africa<br><br>Ronica Subramoney                                                                                                     | To explore the lived experience of Indian women with HIV/AIDS                                                                                      | Kwa-Zulu Natal (KZN), South Africa.<br><br>2015.                        | Lived experience of Indian women with HIV/AIDS   | Questionnaire                                       | 1 hour            | This study highlighted the women's existential life in addition to the total experience of living with the "disease" like separation, struggling, social support system, and struggle with intermittent life.                                                                                                                  | The infected Indian women adopted an approach of hope, and decided to fight with this unalterable situation. They were supported by family, and spiritually. Motivated to move forward in spite of their illness.          |
| 3.    | We have beaten HIV a bit: a qualitative study of experiences of peer support during pregnancy with a HIV Mentor mother project in England<br><br>Jenny McLeish et.al.                           | To explore the experiences of women living with HIV in England or gave mentor mother volunteer peer support during pregnancy and early motherhood. | England.<br><br>2015                                                    | Experience of HIV                                | Semi structured questionnaire                       | 30–86 min,        | Pregnant women and mothers living with HIV were having fear and pain, stigma and loneliness and lack of maternity care which were taken care by Mentor Mother peer support during and after pregnancy emotional support.                                                                                                       | Mentor Mother peer support considered as creating programmes for the support of pregnant women and the prevention of mother-to child transmission of HIV and positive impact on susceptible mothers' emotional well being. |
| 4.    | The lived experience of living with HIV/AIDS in the western region of Saudi Arabia<br><br>Tagwa O. et.al                                                                                        | To explore the experiences of people living with HIV/AIDS in Saudi Arabia                                                                          | King Khalid National Guard Hospital, Jeddah,<br><br>2012.               | Lived experience of living with HIV/AIDS.        | In- depth interview                                 | 30 to 60 minutes. | The outcomes revealed the participants experienced isolation and lack support and all participants accepted their diagnoses as their destiny. They were using spirituality as key coping plan to treat the fears and became more religious,                                                                                    | Participants experienced pessimistic attitude towards self, disgrace.                                                                                                                                                      |
| 5.    | The psychological experience of HIV and AIDS my newly diagnosed infected patients at hospital A of Vhembe District, Limpopo Province<br><br>Ravhel R. et.al                                     | To describe the psychological experiences of infected persons in Hospital A in the Vhembe district of Limpopo Province.                            | Vhembe district of Limpopo Province.<br><br>2012                        | Psychological Experience of HIV and AIDS         | Questionnaire                                       | 1.5 hours         | Self-destructive behaviour was noted. 50% of the participants attempted suicide. The participants worried to expose their status. They expressed that they were going to be stigmatized and rejected by their family members, community.                                                                                       | Living with HIV/AIDS is terrific psychological and physical challenges on every part of daily life.                                                                                                                        |
| 6.    | Challenges faced by people living with HIV/AIDS in Cape Town, South Africa; Issues for group risk reduction interventions.<br><br>Allanise C. et.al.                                            | To investigate the challenges faced by people living with HIV/AIDS in communities                                                                  | Cape Town, South Africa<br><br>2010                                     | Challenges of people living with HIV/AIDS        | Key informant interviews and Focus group discussion | 30 minutes        | The study revealed that AIDS-related stigma remained pervasive in society which was associated with disclosure due to fear of rejection. HIV/AIDS status was secondary stressors of everyday life which result poverty, unemployment, and violence.                                                                            | This study highlighted that the adaptation or development of behavioral risk reduction interventions is needed for PLWHA.                                                                                                  |

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| 7.  | Living day by day: the meaning of living with HIV/AIDS among women in Lebanon<br><br>Rachel L.et.al                                                         | To examine the meaning of living with HIV/AIDS among women to live with HIV/AIDS in Lebanon.                    | Lebanon.<br><br>2010                                    | Meaning of Living With HIV/AIDS                       | Semi-structured questionnaire | 60 to 120 minutes.     | Three major themes reflect both the individual and social impact of HIV/AIDS which were: Stand by my side: Decisions of disclosure; Being "sick" and feeling "normal": Interacting with self, others, and society; and Living day by day: focusing on the present | By accepting their sero-status and by creating new meaning, women are learning to navigate the challenges.                      |
| 8   | Effects of stigmatization on gay men living with HIV/AIDS in a Central Eastern European context; A qualitative analysis from Hungry<br><br>J. Takace, et.al | To analyse the effects of Stigmatization on gay men living with HIV/AIDS                                        | Central Eastern European region in Budapest<br><br>2009 | Effects of stigmatization                             | In-depth interviews           | 1.5 to 2 hours.        | Reducing the unfavourable effects of HIV and homosexuality related stigma were help to Improved the successful rate of HIV prevention, within the gay community.                                                                                                  | One of the main barriers was lack of public health care service. Efforts were needed to minimize the effects of stigmatization. |
| 9.  | The social and health problems of people living with HIV/AIDS in Izmir, Turkey<br><br>Sukran k. et.al.                                                      | To describe how AIDS Associated with stigma affects the lives of HIV positive patients and their family members | Izmir, Turkey<br><br>2007.                              | Social health problems of people living with HIV/AIDS | Semi-structured interview     | January and June 2007. | The finding showed that the main misconceptions were modes of transmission & fear discrimination and stigma which led to survival and employment related problems.                                                                                                | HIV/AIDS related intervention program were helpful to correct the misconception                                                 |
| 10. | The experiences of people living with HIV/AIDS in Gaborone, Botswana stigma, its consequences and coping mechanisms.<br><br>Vincent S. et.al                | To explore the experiences of people living with HIV/AIDS                                                       | Gaborone, Botswana.<br><br>2007                         | Experiences of people living with HIV/AIDS            | Iterative questioning         |                        | The outcomes revealed that PLWHA experienced external and internal (self) stigmatization which led to emotional disturbances, unemployment, poverty, dependence, trouble in relationships.                                                                        | PLWHA felt better when they were counselled by another HIV positive individual than by health professional.                     |

## RESULT:

The result reveals based on the various challenges faced by the people with HIV/AIDS. Respondents had various emotional problems when they came to know that they are infected with the HIV virus and shows that 82.3% of the respondents have emotional problems like guilt, feeling of hopelessness, anger, shocked etc. and among them only 17.7% managed these problems efficiently. South African Indian women living with HIV/AIDS were mentioned about their struggle, isolation, support system, and hope for future and also represent the women's strength to fight with their existential life with the disease. Participants were going through stigmatization and rejection by their family and dear ones and other problems like discrimination, unemployment. Participants were accepted their diagnoses as fortune and became more spiritual which considered as main coping strategy to deal with the fears. Some study shows that there was having significant misconceptions about HIV/AIDS; especially regarding modes of transmission. An educational intervention was needed to correct misconceptions and to minimize the AIDS related stigma in local communities.

### Data analysis reveals four main themes which are described below:

- Disclosure
- Stigmatization
- Psychosocial impact
- Spirituality

**Disclosure:** Participants showing their great concerns regarding disclosure to their HIV positive status with family, friends and others. They experienced major issues in taking decision to whom & when to disclose and also about confidentiality. When participants exposed their condition with others, that time they were judged and blamed by communities.

**Stigmatization:** Stigma is one of the major factors faced by HIV infected participants. The progression of the disease and stigmatization together affected majority of areas like personal, profession, psycho-emotional status. Every connection of participants were strained and disrupted. Participants experienced stigmatization, discrimination, fears and vulnerability, society attitudes and feelings of shame and negative self-image.

**Psychosocial impact:** This review involved with psychological and emotional issues like isolation, hopelessness, anxiety, lack of social support, and refuses to receive treatment. They felt loss of hope, isolating themselves from others to overcome the psychological and social barriers.

**Spirituality:** The emotional status of HIV/AIDS participants was more terrible as physical problems. HIV/AIDS affected every aspect of their quality life like

physical, psychosocial and spiritual. This review focused that majority of HIV infected persons were more religious than before to cope with the diagnosis and its related factors. They search for higher religious power for their smooth harmony of life. The role of religion and spirituality were playing an essential part on emotional well-being. They regularly used to do prayer, deliberation, and faith on God.

### DISCUSSION OF NARRATIVE REVIEW:

This narrative review discovered observed that people living with HIV/AIDS in different nations were high levels incidence of stigmatization and discrimination, fear to disclosure of their status, feeling vulnerability. Family and community support groups were work on shrinking this incidence. Observance of ART treatment is better when family support is more (Manjula A. R. et.al.2016). When people with HIV/AIDS were getting emotional support from them it was more meaningful than counselled by healthcare professional (Vincent S., Anne, W., Ian C. 2007).

The results of this narrative review are similar with one of the other review i.e. "Women living with HIV/AIDS (WLHA), battling stigma, discrimination and denial and the role of support groups as a coping strategy: a review of literature" (Vikas P., Kedar P. B.). This systematic review discovered that women living with HIV/AIDS in different reason of the countries were facing high levels of stigma and injustice from family, society and health workers. HIV/AIDS is much more worse than any physical problem which affected not only body but also affect the human security, rights and social-economic development. The respect and fulfilment of human rights is critically reducing the adverse effect of the disease.

### CONCLUSION:

Based on all ten studies which included in this narrative review, the people with HIV/AIDS are faced major challenges in their entire life. After analyzing these studies, some valuable points are found which are:

- For dealing with HIV related fear, rejection and isolation, the HIV/AIDS infected person was used spiritual coping strategies.
- One study mentioned that HIV/AIDS treatment is better by family support.
- The emotional support by other people living with HIV/AIDS is more meaningful and affective than counselling by healthcare workers.
- People with HIV/AIDS find out some ways to adopt this unalterable situation such as family support, decided to fight against disease and spiritual cop-

ing mechanism to help to move forward despite their diagnosis.

- The role of religious helps to fight against HIV and AIDS epidemic.

**SUMMARY:**

This cited study revealed various aspects and challenges faced by the people with HIV/AIDS. This reviews observed the experience people living with HIV/AIDS in a number of different countries who faced high levels of stigmatization and discrimination from friends, family, community and even health workers, fear to disclosure of their status, feeling vulnerability. Family and community support groups were found to decrease isolation and sense of disgrace, improve self-care behaviors. However in India studies using all steps of the research process are comparatively limited. Thus the review of literature helped the investigator to develop insight into various aspects and challenges faced by the people with HIV/AIDS.

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